

The Golden Retriever Club of America, Inc.

When a beloved Golden is diagnosed with a serious disease, it is an extremely traumatic time for the whole family. However, many owners take comfort in knowing that blood and/or tissue samples submitted to research studies may be able to help reduce, prevent, or treat that same disease in dogs of the future. Below are some tips and information to help guide owners through that difficult time so that they and their Golden may be part of the solution to devastating diseases like cancer, epilepsy, subaortic stenosis (SAS), and others.

Participating in Research: General Tips and Information

Please download and print "How to Participate in Cancer Research" and "How to Participate in Pigmentary Uveitis Research" from the Health Section of the GRCA website (<u>www.grca.org</u>) and ask your veterinarian to place these in your dog's medical chart for easy access in an emergency.

Include a copy of the cancer research document in puppy packets, and ask that the new owner have it placed in the puppy's medical chart for future use.

Depending upon the specific cancer, it is not always necessary to have a definitive diagnosis (such as from a pathology report) prior to submitting a tumor sample. For example, in the case of suspected hemangiosarcoma, samples collected at the time of the initial surgery are very desirable, even though a pathology report has not yet confirmed the diagnosis. Whenever possible, please contact the research study or the research facilitator as soon as a diagnosis is suspected for guidance as to how to support research in the individual circumstances.

Owners will <u>not</u> be asked to alter their treatment plans, to provide a sample that requires surgery that is not in the normal course of diagnosis or treatment, or in any way jeopardize their dog's prognosis or quality of life, for the purpose of participating in research.

In situations requiring emergency surgery when there is no time to contact research labs for specific instructions, please save a blueberry-size tumor sample in a sterile container, and another blueberry-size tumor sample in formalin; refrigerate and contact the research lab as soon as possible for further instructions. In addition, please save and refrigerate 12-15 ml of blood in an EDTA (purple top) tube.

In some cases, when an owner wishes to participate in research but surgery will not be part of the normal course of diagnosis or treatment, tumor samples can be collected immediately post mortem. (An example of this might be when a dog is suspected of having cardiac hemangiosarcoma.) Researchers respect the sensitive nature of this situation and will not request

that an owner do this; but if that is the owner's wish, plans should be made in advance if possible.

Dogs can participate in some cancer studies by providing a blood sample only, so please don't hesitate to contact us even when no tissue sample will be available.

Sometimes the flow of communication is inadvertently interrupted, as when emails are lost in cyberspace, phone messages are garbled, someone is away from email for a period of time, or information is incorrectly relayed from one person to another. If an owner or veterinarian does not receive a timely response or adequate information from one person, <u>please</u> follow up by repeating the contact and/or contacting someone else.

Cancer researchers supported by GRCA and GRF generally work under reciprocal sample sharing agreements. This means that it is usually not necessary for samples to be submitted to more than one cancer research program, because when possible, the samples are shared to make maximal use of these valuable resources. Owners will be asked to initial a consent form giving their permission for samples to be shared, and we request that owners please do this. However, due to specific requirements of individual studies, there are times that samples sent to one researcher are not useful to another.

Dogs with <u>any</u> disease diagnosis can participate in research by submitting a blood sample to the CHIC DNA Repository <u>http://www.caninehealthinfo.org/</u> Even when active studies are recruiting samples (e.g., currently for several kinds of cancer, pigmentary uveitis, etc), DNA from dogs included in current studies is not necessarily available for future studies. Therefore, owners are encouraged to submit a blood sample to the DNA bank <u>in addition</u> to supporting current research studies with tumor and/or blood samples. Diseases of interest include but are not limited to: cancer, SAS, renal dysplasia, swallowing disorders, hip and elbow dysplasia, epilepsy, cataracts, and pigmentary uveitis. There is no charge for enrolling dogs with major diseases, and the fee can be waived by emailing <u>chic@offa.org</u> in advance. Unaffected relatives of affected dogs are also often valuable to store in the DNA repository, as are extremely long-lived dogs.

If blood has been previously submitted to the DNA Repository, such as during a sample drive at a National Specialty or club sponsored event, it is not necessary to resubmit.

Blood samples provided at one of the National Specialty sample drives were divided and shared between the CHIC DNA Repository and the Broad Institute. It is <u>very important</u> to update health histories with BOTH groups when there is a new diagnosis so that "normal control" groups do not inadvertently include affected dogs.

- For the DNA Repository, <u>all</u> disease diagnoses that occurred since the blood was drawn should be updated by email to <u>chic@offa.org</u>
- For the Broad Institute, all <u>cancer</u> diagnoses that occurred since the blood was drawn should be updated by using the Health Update Form at <u>www.dogdna.org</u>

It is sometimes difficult for owners and veterinarians to know whom to contact, and in such circumstances, please contact the Research Facilitator using the information provided below.

Please know that the researchers involved in sample collection truly do care about the dogs and their human families. All are very aware that the circumstances are usually heartbreaking, and will try to make the sample donation process go as smoothly as possible. Should any questions or concerns arise, please do not hesitate to contact me.

Rhonda Hovan GRCA Research Facilitator 330-668-0044 hm 330-338-4236 cell <u>rhondahovan@aol.com</u>